

Understanding NICE guidance

Information for people who use NHS services

Borderline personality disorder

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with borderline personality disorder in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with borderline personality disorder but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe borderline personality disorder or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 16. Medical terms printed in **bold** type are explained on pages 14 and 15.

Contents

Your care	3
Borderline personality disorder	4
What happens when I first see a healthcare professional?	5
Who will provide my treatment?	7
What treatment should I be offered for borderline personality disorder?	9
What should happen in a crisis?	11
Can I have treatment for other conditions?	12
What happens when treatment comes to an end?	12
Information for families and carers	13
Glossary	14
More information	16
About NICE	16

The advice in the NICE guideline covers:

- The care, treatment and support that people with borderline personality disorder should be offered.

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain borderline personality disorder and the treatments for it simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible, but this does depend on your age. If you are over 16, or under 16 and fully understand the treatment, you may be able to give your own agreement. If you are too young, your parents or **carers** may need to agree to your treatment.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree to them being involved, your family and carers should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Health Capacity Act. For more information about this visit www.publicguardian.gov.uk

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

Borderline personality disorder

Borderline personality disorder is a condition that affects a person's thoughts, emotions and behaviour. It is not usually diagnosed before the age of 18 but symptoms can be recognised in younger people. 'Borderline' was originally used by psychiatrists to suggest that the condition was thought to be on the 'border' of other psychiatric problems. Some experts think that this is no longer the most appropriate term to use.

The symptoms of borderline personality disorder include:

- having emotions that are up and down (for example, feeling confident one day and feeling despair another), with feelings of emptiness and often anger
- difficulty in making and maintaining relationships
- having an unstable sense of identity, such as thinking differently about yourself depending on who you are with
- taking risks or doing things without thinking about the consequences
- harming yourself or thinking about harming yourself (for example, cutting yourself or overdosing)
- fearing being abandoned or rejected or being alone
- sometimes believing in things that are not real or true (called delusions) or seeing or hearing things that are not really there (called hallucinations).

A person diagnosed with borderline personality disorder will have most of these symptoms and they will have a significant impact on their life.

People with borderline personality disorder come from many different backgrounds, but most will have suffered some kind of trauma or neglect as children.

Just under 1% of people have borderline personality disorder. Some of those people may also have other conditions such as **depression**, anxiety (feelings of worry or fear that can be difficult to control), an **eating disorder**, **post-traumatic stress disorder** or **bipolar disorder**, or problems with drugs and alcohol.

Although some people may have borderline personality disorder for a long time, many do recover from the condition.

What happens when I first see a healthcare professional?

If your GP thinks you may have borderline personality disorder, you should be offered an appointment with your **community mental health service** for an **assessment**.

In your assessment the healthcare professional should clearly explain the process, and what having borderline personality disorder means. They will ask you about your thoughts, feelings and behaviour and how you cope with any problems in different areas of your life, including any other mental health problems. They will also discuss with you whether you need **psychological treatment**, social care and support in getting suitable education, training or work. They should develop a plan (called a care plan) for your treatment and care.

Your healthcare professional should also discuss with you any behaviour that may be a risk to yourself or others. This is so that together you can develop a plan to get the right care and support.

If you need support after the assessment, particularly if you have been asked about any sensitive or distressing issues, your healthcare professional will be able to arrange it for you.

If you have a mild learning disability, your assessment should be done in consultation with a specialist in learning disabilities. You should be offered the same services as other people with borderline personality disorder. People with a moderate or severe learning disability should not normally be given a diagnosis of borderline personality disorder. However if a healthcare professional thinks that the person's symptoms and behaviour suggest a personality disorder, they should be offered an assessment with a specialist in learning disabilities.

If your first contact with healthcare services is after you have harmed yourself, you should be treated according to the NICE guideline on **self-harm**¹.

If you are offered an appointment for an assessment with another service (including for psychological treatment) you should still be offered support while you are waiting for an appointment.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

¹ See www.nice.org.uk/CG16

Young people (under 18) with borderline personality disorder (or problems that suggest that they may have borderline personality disorder)

If a professional in health, social care or education is concerned that a young person may have borderline personality disorder they should offer them an appointment with child and adolescent mental health services for an assessment.

Young people should be offered the full range of treatments described in this booklet within child and adolescent mental health services.

Young people with severe symptoms should be able to receive specialist treatment. This may be in hospital (either staying over night or as an outpatient) or at home.

The young person may still receive care from child and adolescent mental health services even after they turn 18, if this is in their best interests.

Questions you might like to ask your healthcare team

- Why have I been given this diagnosis?
- Can I expect a positive outcome from treatment?
- Who can I contact in a crisis?
- Are there any support organisations in my local area?
- Can you provide any information for my family or carers?

Who will provide my treatment?

You should receive most of your treatment from your community mental health service (this might include a personality disorder service where available), although your GP may be involved in your physical health needs and support in a crisis. If you harm yourself you may receive some treatment from the ambulance service and A&E.

Your healthcare team, together with you and your family or carers (if you agree to them being involved), should develop a plan for your treatment. This plan should say who is responsible for different aspects of your care, what you hope to achieve from treatment in the short and long term (including goals relating to education, training or work), and what needs to happen to help you achieve this. It should also identify what may lead to you having a crisis, how you can help yourself during these times, and what to do if you need further support, such as help from out-of-hours teams and crisis teams.

People with borderline personality disorder should receive most of their care in the community, but may need treatment in hospital in rare circumstances. Healthcare professionals should offer other services, such as crisis teams, that can provide treatment and care in the person's home, before considering admission to hospital. People should only be admitted to hospital if there is a crisis and a great risk to the person or others, or if the person needs treatment under the **Mental Health Act**.

If your healthcare professional thinks that a stay in hospital would help you, they should involve you in the decision. They should agree with you before you go into hospital how long the stay should last and why you are being admitted. If you have been in hospital for treatment for borderline personality disorder on two or more occasions in the past 6 months your treatment and care should be reviewed.

If you have talked to your healthcare team, and you think that a treatment is suitable for you but it is not available, you can contact your local patient advice and liaison service ('PALS').

Your rights and your relationship with your healthcare team

You should not be excluded from any services because of a diagnosis of borderline personality disorder or your ethnicity, or if you have self-harmed.

Your healthcare team should work with you to help you to make your own decisions about your treatment options and goals. You should be encouraged and supported to find solutions to your problems, including during a crisis, because this will help to build your confidence.

Your healthcare team should build a relationship with you based on hope, optimism and trust. Healthcare professionals should be non-judgemental, consistent and reliable. They should also be aware of any sensitive issues such as fears of rejection, possible abuse and trauma, or self-harm, and issues related to receiving a diagnosis of borderline personality disorder. Options for treatment should be fully explored with you and it should be explained that recovery from borderline personality disorder is possible and achievable.

Will my family or carers be involved in my treatment and care?

Healthcare professionals should ask you whether you wish your family or carers to be involved in your care. If you agree, they should encourage your family or carers to be involved.

There is information for families and carers on page 13.

What treatment should I be offered for borderline personality disorder?

Psychological treatment

If borderline personality disorder causes you many problems, or you have other conditions, you may be offered a psychological treatment in a special programme usually run by a team of people. This will be based on an approach that you, the therapist and the team agree to in advance. The treatment should be properly structured as described in the NICE guideline. How often you have sessions will depend on your needs and how you live your life. Psychological treatment lasting about a year or longer is best for people with borderline personality disorder.

Your healthcare professional should offer you written information about the treatment and how it can help you. They should also offer to discuss the information with you and talk about how helpful other psychological treatments are in treating borderline personality disorder and other conditions. People with reading difficulties should be given the information in another format, such as video or DVD.

Women with borderline personality disorder who self-harm on a regular basis may be offered a treatment called **dialectical behaviour therapy**.

Your care team should check periodically that the psychological treatment is helping your symptoms and helping you in different areas of your life.

Should I be offered medication?

You should not usually be offered medication specifically to treat borderline personality disorder or for any related symptoms or behaviour (such as self-harm, unstable moods and risky behaviour). This includes a type of medication called an **antipsychotic** as a long-term treatment.

However, you may be offered medication called a **sedative** for a short time (no longer than a week) to help you in a crisis (see page 11). You may also be offered medication to treat another mental health problem (see page 12).

If you are offered medication for any reason, your healthcare professional should offer you written information about the effect it will have on your symptoms and any side effects. It should also be explained to you why the medication may be helpful for you at this time. Your healthcare professional should also offer to discuss the medication with you further. People with reading difficulties should be given the information in another format, such as a video or DVD.

If you are currently taking medication but do not have another condition (either a physical or a mental health problem), this treatment should be reviewed by your healthcare professional and stopped if necessary.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

Questions about treatment

- Why have you offered me this type of treatment?
- What are the pros and cons of having this treatment?
- Please tell me what the treatment will involve.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Are there any risks associated with this treatment?
- What are my options for treatments other than the recommended treatment?
- What will happen if I choose not to have the recommended treatment?
- Is there some written material (like a leaflet) about the treatment that I can have?

What should happen in a crisis?

If you are having a crisis and you go to see your GP, they should assess whether there is a risk to yourself or others. They should ask about similar crises in the past and what has helped you to cope with them. Your GP should help you to cope with your anxious feelings, for example by focusing on the immediate problem. They can encourage you to look at any changes you can make in your thinking or behaviour that will help you to deal with the immediate problem. You should be offered another appointment with your GP at a time that is suitable for you.

Your GP may offer you an appointment with your community mental health service if you are getting more distressed or if there is a risk to yourself or others, or if you would prefer to see your community mental health team.

If you see your community mental health service in a crisis, they should follow your care plan (see page 5). They should try to understand the crisis from your point of view, and explore with you why you are distressed. They should be sensitive about why you are having a crisis and encourage you to think about solutions for your problems. They should try to help you to work through your problems rather than immediately offering you a place in a crisis unit or hospital. You should be offered another appointment with your community mental health service at a time that is suitable for you.

You may be offered medication to help you in a crisis for short periods. You should usually be offered only one medicine at a time. Your healthcare professional should explain what the medication is for, how often they should see you while you are taking the medication and how long the treatment should last (usually no longer than a week). They should also discuss with you how to take the medication as prescribed. If the medication does not appear to be helping you, then it should be stopped. You may be offered a psychological treatment if you do not feel better.

Once the crisis has passed you should be offered an appointment to look over your care plan to make sure it is right for you. Your healthcare professional should update your plan with you and your family or carers (if you agree to them being involved) as soon as possible to record any concerns and any treatments that have been helpful or unhelpful.

If during a crisis you need to take medication for longer than a week, your healthcare professional should see you regularly at times that suit you.

Questions about medication

- How long will I have to take the medication for?
- Might I have problems when I stop taking the medication?
- Are there any serious side effects associated with this medication?
- What should I do if I get any side effects? (For example, should I call my GP, or go to the emergency department at a hospital?)
- Are there any long-term effects of taking this treatment?

Can I have treatment for other conditions?

People with borderline personality disorder often have other conditions, such as depression, anxiety, an eating disorder, post-traumatic stress disorder, bipolar disorder and drug and alcohol problems. Before you are treated for these conditions, your healthcare team should review your diagnosis (of both borderline personality disorder and any other condition) and look at all the treatments you have had. Any treatment that is not helping should be stopped.

You should be able to have treatment for depression, post-traumatic stress disorder or anxiety at the same time as having treatment for borderline personality disorder. If you have another condition you may be offered psychological treatment and/or medication for this as recommended in the appropriate NICE guideline.

People with severe hallucinations (seeing or hearing things that are not really there) and/or delusions (sometimes believing in things that are not real or true), problems with alcohol or drugs or a severe eating disorder may be offered an appointment with another service for treatment. A care coordinator should keep in contact with the person so that they continue treatment for borderline personality disorder when the time is right.

If you have problems getting to sleep you should be offered advice about having a good sleep routine, avoiding caffeine and cutting down on things that may keep you awake (such as television). You may be offered medication, such as a **sedative antihistamine**, if your healthcare professional thinks this may help.

What happens when treatment comes to an end?

When your community mental health service (which may include a personality disorder service) thinks that you are well enough to leave the service, your care will be transferred to a primary care professional such as a GP for continued support. This should be discussed with you and your family or carers (if you agree to them being involved) in advance. Together you should also agree a plan that sets out the steps you can take to cope with crises and how you can contact your community mental health service again if needed.

When treatment comes to an end this should be discussed with you in advance and should not happen abruptly. The ending of treatment or your time with the service should take place over a period of time.

Information for families and carers

Living with a person with borderline personality disorder can be difficult and challenging. Families and carers can play an important part in supporting a person with borderline personality disorder, especially if the family member or friend is young. But families and carers may also need help and support themselves. Healthcare professionals should give you information about local family and carer support groups.

It is up to the person with borderline personality disorder whether they would like family members or carers involved in their treatment. They might ask for you to be involved or this might be encouraged by their healthcare professional. But if the person with borderline personality disorder would prefer to cope on their own, you are still entitled to an assessment of any physical and mental health needs you have, and to support.

Questions for families and carers

- Please give me some information about borderline personality disorder and its treatments.
- Am I entitled to be told about the treatment my family member or friend is having?
- What can I/we do to help and support the person with borderline personality disorder?
- Can you give me any information about how to get help and support in a crisis?
- Is there any additional support that I/we as carer(s) might benefit from or are entitled to?

Glossary

Antipsychotic: a type of medicine that is sometimes used to treat serious changes in mental state (such as hallucinations and delusions).

Assessment: a meeting with a healthcare professional in which they will ask questions about your physical and mental health, to establish what the illness is, how severe it is and what treatments would suit you best.

Bipolar disorder: a type of mental health problem sometimes known as manic depression. It is a disorder that affects mood, in which a person alternates between feeling low (called depression) and feeling very 'high', happy and over-confident (called mania).

Carer: a person (such as a family member or a friend) who has regular close contact with the person with borderline personality disorder and is involved in their care.

Community mental health service: a group of professionals or a healthcare service that includes nurses who may visit people in their own home, psychiatrists, psychologists, occupational therapists, social workers and support workers.

Depression: a type of mental health problem that causes a loss of pleasure in things that were once enjoyable, withdrawal from family and friends, negative and self-critical thoughts, and other symptoms, such as feeling tearful, irritable or tired, poor appetite, and sleep problems.

Dialectical behaviour therapy (sometimes called DBT): an intensive psychological treatment that focuses on enhancing a person's skills in regulating their emotions and behaviour. It aims to address and alter patterns of behaviour by finding a balance or resolving differences (this is what is meant by 'dialectical'). The therapy can help a person gain control of behaviour such as self-harm and substance misuse. The therapy usually takes place over 1 year with weekly one-to-one and group meetings.

Eating disorder: an illness that affects how people feel about their body shape and weight. Common kinds of eating disorder are anorexia nervosa and bulimia nervosa.

Mental Health Act: a law that allows a person with a mental disorder to be treated against their will, or without their agreement, if they are judged to be a serious risk to themselves or others. This is sometimes called 'being sectioned'. A person treated under the Mental Health Act will receive care in hospital where they can expect as much care and support as anyone else. People treated under the Mental Health Act have a legal right to appeal.

Post-traumatic stress disorder: psychological and physical problems that can sometimes follow threatening or distressing events.

Psychological treatment: a general term used to describe meeting with a therapist to talk about feelings and moods.

Sedative: a type of medication that helps a person feel relaxed and sleepy.

Sedative antihistamine: a type of medication used to treat a range of ailments including allergies and skin problems, which have non-addictive properties that can also help people sleep and calm them down.

Self-harm: an expression of personal distress by an individual who hurts him or herself. Common methods of self-harm include cutting oneself and taking too many tablets or recreational drugs.

More information

The organisations below can provide more information and support for people with borderline personality disorder. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Borderline UK Ltd, www.borderlineuk.co.uk
- BPDWORLD, 0870 005 3273, www.bpdworld.org
- Rethink, 0845 456 0455, www.rethink.org
- SANE, 0845 767 8000, www.sane.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing service users, families and carers. They consider the best available evidence on the condition and treatments, the views of service users and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG78

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk) and quote reference N1766).

We encourage NHS and voluntary organisations to use text from this booklet in their own information about borderline personality disorder.

The NICE website also has information about the guidelines on antisocial personality disorder, anxiety, bipolar disorder, depression, drug misuse, eating disorders, post-traumatic stress disorder and self-harm.